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Speaking Up for Fundamental Care

the ILC Aalborg Statement

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BMJ Open Speaking Up for Fundamental Care: the ILC Aalborg Statement

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ABSTRACT

Objective The International Learning Collaborative (ILC) is an organisation dedicated to understanding why fundamental care, the care required by all patients regardless of clinical condition, fails to be provided in healthcare systems globally. At its 11th annual meeting in 2019, nursing leaders from 11 countries, together with patient representatives, confirmed that patients' fundamental care needs are still being ignored and nurses are still afraid to 'speak up' when these care failures occur. While the ILC's efforts over the past decade have led to increased recognition of the importance of fundamental care, it is not enough. To generate practical, sustainable solutions, we need to substantially rethink fundamental care and its contribution to patient outcomes and experiences, staff well-being, safety and quality, and the economic viability of healthcare systems.

Key arguments We present five propositions for radically transforming fundamental care delivery:

1. Value: fundamental care must be foundational to all caring activities, systems and institutions
2. Talk: fundamental care must be explicitly articulated in all caring activities, systems and institutions.
3. Do: fundamental care must be explicitly actioned and evaluated in all caring activities, systems and institutions.
4. Own: fundamental care must be owned by each individual who delivers care, works in a system that is responsible for care or works in an institution whose mission is to deliver care.
5. Research: fundamental care must undergo systematic and high-quality investigations to generate the evidence needed to inform care practices and shape health systems and education curricula.

Conclusion For radical transformation within health systems globally, we must move beyond nursing and ensure all members of the healthcare team—educators, students, consumers, clinicians, leaders, researchers, policy-makers and politicians—value, talk, do, own and research fundamental care. It is only through coordinated, collaborative effort that we will, and must, achieve real change.

'WICKED PROBLEM'

One would think, with all the resources health systems continue to put into safety and quality initiatives; the implementation

of more person-centred care policies; and the proliferation of agencies to regulate and demand better fundamental care for patients (eg, Care Quality Commission in the UK, US Agency for Healthcare Research and Quality, and Australian Commission on Safety and Quality in Health Care), that the tide would be turning. However, this does not seem to be the case, as illustrated by recent reports of continued poor practices.¹ A nurse turning away from a patient in a single episode of suffering is worrying in itself. However, when this action becomes the norm, when it is tolerated and even normalised within teams and institutions, it is necessary to reflect critically on why patients are treated in such dehumanising ways,² and what can be done to ensure patients receive safe, dignified care for their fundamental needs.

The International Learning Collaborative (ILC) is an organisation set up to understand why fundamental care fails to be provided in our healthcare systems. At its 11th annual meeting in 2019, hosted by Aalborg University and Aalborg University Hospital in Denmark, nursing leaders from 11 countries, together with patient representatives, confirmed that fundamental care is still failing to be delivered consistently. Patients are still being ignored and 'commodified' and nurses are still afraid of 'speaking up' when fundamental care failures happen.

Personal experiences from nursing colleagues and patients outlining fundamental care breaches were all too readily available. One nurse recounted her story of being in an emergency department caring for a patient who needed a CT scan. The patient had to be moved to the X-ray department and then to a ward. Before this happened, the patient was incontinent of urine, soaking the bed and himself. The nurse went to find clean linen and pyjamas but was told by the nurse-in-charge that there was no time to do this



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as the department would fail its 4-hour discharge target if there was a delay. The nurse ignored the instruction from the nurse-in-charge, instead meeting the patient's fundamental care needs, but was made to feel she had done something wrong. Another nurse told the story of her father-in-law who lost several kilos in weight over the course of a 10-day hospital stay. He was discharged frail, weak and vulnerable, with no guidance or support offered to the patient and family. Even as a nurse, she felt unable to challenge what was happening to him.

Patient representatives at the meeting confirmed that these types of dehumanising actions were familiar to them. One cancer survivor spoke about having survived but was traumatised by the experience of care. Another survivor recounted a conversation with a nurse who said to the patient, when about to start chemotherapy, that if it had been her, she would not have agreed to the treatment. These stories resonated with nursing leaders attending the ILC meeting from Australia, New Zealand, Japan, Iceland, Norway, Sweden, Denmark, the Netherlands, Canada, the US and the UK. These stories are also strongly supported by existing empirical evidence, spanning more than a decade of research, regarding patients' views and experiences of care across a range of health-care settings and systems.^{3 4} This research demonstrates the central importance that patients place on their relationships with care providers, and the need for nurses to display not only technical competence in relation to physical aspects of healthcare but also relational competence, where patients' psychosocial needs are integrated and addressed in every episode of care.⁵⁻¹²

This existing evidence—both empirical and anecdotal—would seem to indicate that we continue to have a problem; not an isolated one, but one that has infected every health system globally. It would also seem that we cannot solve it by doing more of the same. We need to rethink fundamental care and its contribution to patient and staff well-being, patient safety and quality, and the economic viability of our healthcare systems.

PROPOSED SOLUTION ...

In addition to trying to understand the reasons for the fundamental care failures in our healthcare systems, at the 2019 ILC meeting we worked on finding different ways of addressing the issue, moving to practical and sustainable solutions. We identified five essential ingredients needed for this transformation. These are presented as five propositions:

1. Value fundamental care: fundamental care must be foundational to all caring activities, systems and institutions.
2. Talk fundamental care: fundamental care must be explicitly articulated in all caring activities, systems and institutions.
3. Do fundamental care: fundamental care must be explicitly actioned and evaluated in all caring activities, systems and institutions.

4. Own fundamental care: fundamental care must be owned by each individual who delivers care, who works in a system that is responsible for care or who works in an institution whose mission is to deliver care.
5. Research fundamental care: fundamental care must undergo systematic, high-quality investigations to generate the evidence needed to inform care practices and shape health systems and education curricula.

Value fundamental care

The ILC has been systematically developing definitions around fundamental care¹³ and has developed an evidence-based framework^{14 15} to help nurses implement fundamental care in a more consistent way. The Fundamentals of Care Framework consists of three core dimensions. These are: (1) the development of a positive, trusting relationship between the nurse (or other care provider) and patient; (2) integrating and attending to, in every episode of care, a patient's physical (eg, nutrition), psychosocial (eg, dignity) and relational needs (eg, empathy); and (3) being cognizant of how the context in which care takes place can facilitate or hinder the accomplishment of the first two activities, working to mitigate or enhance these impacts where possible.¹⁵

Our argument is that regardless of clinical condition, age, acuity, complexity, or care setting, every patient will require their fundamental care needs to be assessed and met for them to be safe and to recover optimally. Current failures in our health systems, including the poor level of remuneration for nurses delivering fundamental care, are directly related to the lack of value placed on fundamental care as a foundational cornerstone to safety and quality.

Our proposal is that if executive boards and shareholders in caring and healthcare businesses recognised and acknowledged the importance of fundamental care to their financial success, then appropriate systems and processes would be put in place, and would be more effective and efficient, leading to improved patient outcomes and better staff satisfaction.

Talk fundamental care

Only after executive leaders and shareholders understand the value of delivering fundamental care consistently to all patients (customers) will the language of fundamental care be more readily accepted and understood. Commonly, nursing care patient notes are regarded as 'fluffy notes', rarely referred to by other members of the healthcare team.¹⁶ The 'knowledge hierarchy' cascades from the medical to allied health notes and finally to nursing notes (where some aspects of patients' fundamental care needs are recorded). Consequently, nursing activities tend to relate to risk assessments, safety reports or concerns over clinical/medical activity.

This reality carries with it profound risks to both patients and nurses. When nothing or very little about fundamental care is documented in patients' records, it is impossible to tell what has been provided and what has

not. Electronic patient records do not solve this problem as they have been constructed within the medical hierarchy, hence fundamental care is still invisible.

Our argument is that by using the core dimensions of the Fundamentals of Care Framework (relationship, integration of care and context), we can generate consistent and meaningful summaries of patients' fundamental care needs. By investing in infrastructure and workflow systems that comprehensively record these needs, we will be able to document what interventions were undertaken and what impact they had. Then we will be able to teach fundamental care more consistently, addressing the ever-present 'theory-practice' gap.¹⁷

Our proposal is to extend the complex mapping work needed to generate consistent terminology around fundamental care and how it is documented, and to invite interdisciplinary colleagues, managers and educators to engage in this dialogue.

Do fundamental care

Having fundamental care valued by organisations and having done the work around conceptual frameworks, terminology and education, we then need to commit to making fundamental care happen in a consistent, safe, person-centred way for all patients, independent of care setting. This will require a significant shift in culture for many nurses (and every other member of the care team). Traditionally, nurses have been rewarded for the speed with which they can accomplish multiple tasks within rigid timeframes. This 'task and time' mentality is the antithesis to the values of fundamental care delivery based on relationship and integration of care.¹⁵ How whole nursing teams (and consequently interdisciplinary care teams) must redesign their fundamental care delivery systems will be a huge transformational activity. It will require redesign teams to work collaboratively with nurses, patients, and other key stakeholders to turn fundamental caring systems and processes 'up-side-down'. It will also require the development of standardised ways of measuring fundamental care that are embedded in patient records and can inform risk assessments as well as safety, quality and outcome metrics.¹⁸

Our argument is that because the 'task and time' culture is so deeply embedded in nursing and healthcare, there needs to be a paradigm shift in work processes related to fundamental care delivery. We must move from a 'task and time' mentality to a 'thinking and linking' mental model, where nurses are able to integrate and coordinate patients' fundamental and other care needs across their healthcare experience.¹⁹ To be effective, this shift must occur at all levels of healthcare systems: the micro level (eg, in nurses' attitudes, behaviours and everyday interactions with patients), meso level (eg, in the culture and policy of a single organisation, including at a unit/ward level) and macro level (eg, in national health policies and nursing accreditation standards for clinical practice and education). This shift is crucial if healthcare systems worldwide are to achieve the goal of person-centred care,

which is at risk of becoming mere rhetoric. Delivering high-quality fundamental care is a key prerequisite for working with patients in a person-centred way. If we are to move beyond mere rhetoric, healthcare professionals must have the tools to achieve person-centred fundamental care in practice and to move their care delivery from a series of tasks to a coordinated, integrated, relationship-centred healthcare encounter.

Our proposal is to call for collaborating healthcare organisations and universities to work with the ILC to systematically and rigorously undertake this transformation, generating evidence of impact through cultural change and the development of appropriate measures as we work together to improve patients' fundamental care experiences.

Own fundamental care

We must ask ourselves what healthcare organisations would look like if we put fundamental care at the centre of all that we do. Certainly, there are flagship institutions where patients are satisfied with their care, where nurses feel happy and fulfilled in their caring roles and where medical and quality-of-life outcomes are exemplary. However, these are the exception rather than the rule and we need urgently to own the agenda to make fundamental care more visible in our health systems. There are many practical things we can do such as ensuring fundamental care stories (good and bad) are presented to executive board members and to local and national politicians; having fundamental care explicitly embedded in policies, safety and quality standards, educational standards and research tenders; and making sure that nursing leaders globally speak up for fundamental care.

Yet, we know that in many countries, nursing is facing severe shortages due to issues such as poor recruitment into the profession and poor retention during nursing education and early career employment; an ageing population, which is creating greater demand for health services; an ageing nursing workforce; and strategic understaffing of registered nurses within healthcare systems in an attempt to reduce healthcare costs.^{20–22} Perhaps most worrying, the shortage is also underpinned by many nurses' decision to leave the profession, citing burnout, stress, understaffing, high workloads, minimal job satisfaction, emotional exhaustion and poor patient safety as reasons.^{23–28} Many nurses talk about the disappointment and disillusionment of wanting to care for patients in an holistic way but being unable to do this in the systems in which they work.²⁹ Increasingly, and perhaps unsurprisingly, international research is identifying that what many nurses are required to prioritise is technical care over fundamental care,³⁰ which leads to missed care^{30 31} or, worst case scenario, patient neglect or harm.^{32–34}

However, workforce shortages cannot be an excuse for failure to address fundamental care needs. Neither can the mantra of busyness. Fundamental care is core to nursing values and nursing work. Nurses should not be 'too busy' to deliver it. Devaluing fundamental care

and its importance devalues nursing and its importance. The notion that core nursing work can be performed by cadres of lower-educated care assistants is only burying the problem. This might solve a workforce shortage but it will increase the risk of harm to our patients. Our recent ILC meeting reflected the concern that patients also have with these issues. As stated by one of the patient representatives at the meeting: more nurses are not the only answer—there needs to be a total redesign of how fundamental care is valued in the system.¹

Research fundamental care

Recent reports have identified poor fundamental care practices with care being standardised and patients being objectified (see *Journal of Clinical Nursing Special Issue on Fundamental Care: The Last Evidence-free Zone*, 2018, <https://onlinelibrary.wiley.com/toc/13652702/2018/27/11-12>). Fundamental care tends to be devalued, and the delivery of safe, person-centred care is challenged.³⁵ Although studies have stressed that nursing care is important for patient safety, recovery and positive patient experiences,^{36 37} there is a pressing need to generate studies that demonstrate the benefits of fundamental care in order to strengthen the evidence base. For example, in a recent systematic review,³⁸ the authors note in their quality appraisal of 149 experimental studies into nursing care for the fundamentals of nutrition, hygiene, toileting and mobility, that all but 13 studies had significant biases and only one had clear practice implications for delivering fundamental care in routine nursing care environments.

We also need systematically to evaluate the redesign of care delivery systems that put the patient and their fundamental care needs at the centre. We need sound economic evaluation of the investment required and to off set that with improvements in health outcomes, throughput, and safety and quality indicators. We need to research how we teach fundamental care to nursing students^{39–43} and we need to understand how fundamental care is embedded in policies and legislation at national and local levels.⁴⁴

Our argument is that the current problems healthcare systems are facing could be solved by more investment into research programmes that investigate how to deliver high-quality fundamental care in multiple contexts and how to embed this evidence into nursing (and other) healthcare curricula. There are some exemplars of this, including the Basic Care Revisited research programme in the Netherlands,⁴⁵ the fundamental care theme of the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care Wessex,⁴⁶ and the pioneering work of ILC members (see *Journal of Clinical Nursing Special Issue*), but this work needs to be scaled up and coordinated in a way that will start to offer solutions to healthcare systems sooner rather than later. We must stop wasting tax payers' money in every country by thinking fundamental care failures can be fixed by (at best) naive or (at worst) knee-jerk policy initiatives that do not address the underlying problems.

Our proposal is to work with national governments, healthcare organisations, research funding bodies, universities, and national and international nursing associations, to generate a collaborative research and implementation programme on fundamental care.

CALL TO ACTION

We need to recognise the profoundly complex nature of the challenge facing all healthcare systems globally. We need to acknowledge that how we are trying to fix the problem is not working and we need to think differently. We need a call to action that connects the valuing, talking, doing, owning and researching of fundamental care.

With a membership base now spanning 22 different countries, the ILC has grown rapidly in recent years, and made significant inroads, however, it is clear we cannot do it alone. And while other commentators have identified the need for action around 'reconciliation, refocus and research' (Richards and Borglin, p151)¹ on fundamental care, we need a more concerted, explicit approach.

For the Call to Action to work we must move beyond nursing and involve all members of the healthcare team: educators; students; consumers; clinicians; executives, managers and leaders; researchers; policy-makers; the general public and politicians. We must all work together to initiate and sustain real change and must do so in a coordinated, collaborative way.

Our proposal is thus the Call to Action for Fundamental Care.

If you want to Value, Talk, Do, Own and Research Fundamental Care, please contact us at intlearningcollaborative@gmail.com or <https://intlearningcollab.org/>

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